CHAPTER 2. PROGRAM SERVICES

2.1 Referral

Primary referral sources include, but are not limited to: self-referrals (parent/caregiver), hospitals, Trauma Centers, rehabilitation centers, Physicians, local schools, Public Health Agencies, social service organizations, emergency medical staff, and community health nurses (CHN), other health care providers and community organizations.

A. Traumatic Brain Injury (TBI)
Referrals may be made by contacting the Family Resource Coordinator within the community or corresponding county of residence, the Children' s Information Hotline at 1-800-232-1676 or the Office for Children with Special Health Care Needs at (602) 542-1860.

B. Spinal Cord Injury (SCI)
Referrals may be made by contacting the Family Resource Coordinator within the community or corresponding county of residence, the Children' s Information Hotline at 1-800-232-1676 or the Office for Children with Special Health Care Needs at (602) 542-1860.

C. Children and Youth with Special Health Care Needs (CYSCHN)
Referrals may be made by contacting the Family Resource Coordinator within the community or corresponding county of residence, the Children' s Information Hotline at 1-800-232-1676 or the Office for Children with Special Health Care Needs at (602) 542-1860.

2.2 Intake

Intake is the process of a Family Resource Coordinator responding to the referral and providing information to the family regarding the TBI/SCI/CYSHCN Family Resource Coordination Program.

A. The Family Resource Coordination Contractor is required to acknowledge receipt of referral by contacting the family by telephone or letter within five (5) business days to initiate the intake process.

B. The referral date, intake date, and the referral source are documented on the Intake form for all intakes

C. The Family Resource Coordinator completes the intake process in the home or other location as specified by the family.

D. The Family Resource Coordinator responds to questions and requests for information about the child' s special needs and possible services available at state and local levels.

E. The purpose of the Family Resource Coordination Program is reviewed with the family.

F. The outcome of the intake process is a determination of a family' s desire to receive services through the TBI/SCI/CYSHCN Family Resource Coordination Program.

G. If the family indicates they do not want to receive services from the TBI/SCI/CYSHCN Family Resource Coordination Program, a Program Transfer/Exit

Form is completed. The exit date and exit reason is documented on the Program Transfer/Exit Form and on the Family Resource Coordination Detail Sheet of the Billing Invoice Packet.

H. If the family indicates that they would like the child to receive services through the TBI/SCI/CYSHCN Family Resource Coordination Program, the child/youth becomes a member and is considered enrolled in the program. A signed Authorization for Release of Information shall be obtained from the member, parent, or guardian.

I. When a child, youth, or family is experiencing an urgent situation and seeking immediate assistance, an Emergency Intake may be done. " Emergency Intake" and the program the child/youth is enrolling in (TBI, SCI, or CYSHCN) are checked on the Intake form, and the " Member' s Information" section of the Intake form is completed. The Emergency Intake date is documented on the Intake form, and on the Family Resource Coordination Detail Sheet of the Billing Invoice Packet. An Authorization for Release of Information shall be signed by the member, parent, or guardian.

2.3 Indicators

Traumatic Brain Injury (TBI)

Children/youth who are survivors of traumatic brain injury sustained before the age of 18 may receive Family Resource Coordination services. Young adults may continue to receive services, as needed, until age 21. Receipt of Family Resource Coordination services is based upon self/caregiver report and/or medical documentation of a traumatically induced physiological disruption of brain function as a result of:

The head being struck
The head striking an object
The brain undergoing an acceleration/deceleration movement without direct trauma to the head
Hypoxia/anoxia related disruptions in brain function because of a traumatic event

Head injury does not include vascular accidents, aneurysms, and congenital defects. Excluded are disruptions in brain function caused by stroke, tumor, encephalitis, etc.

Spinal Cord Injury (SCI)

Children/youth who are survivors of a spinal cord injury sustained before the age of 18 may receive Family Resource Coordination services. Young adults who qualify may continue to receive services, as needed, until age 21. Receipt of Family Resource Coordination services is based upon self/caregiver report and/or medical documentation of a severance or severe injury to the spinal cord and or nerve roots caused by trauma which may result in partial or total paralysis of the arms or legs or both and which may also impair vital functions and motor functions defined as:

Acute traumatic injury of the spinal cord and nerve roots
Motor and sensory deficits

Children with Special Health Care Needs (CSHCN)

Children/youth birth to 21 years of age, who present with a broad range of disabilities or chronic illnesses diagnosed at any time during childhood, including the prenatal period, may receive Family Resource Coordination services through this program component.

Such chronic conditions may necessitate adaptations, support, and or special services. Children/youth with special health care needs may require:

Prolonged or periodic inpatient or outpatient hospitalizations that are longer than the average stay or with greater frequency than the general population
Adaptations for daily living due to health related functional limitations
A special level of expertise for treatment and/or services from multiple disciplines
Special services in educational settings

2.4 Individual Service Plan (ISP)

The fully completed Individual Service Plan (ISP) serves as the guiding document for identifying desired outcomes, resources, priorities and concerns, and the strategies to meet identified goals. Individual Service Plans shall contain:

A. The member' s current status, including present levels of functioning in physical, cognitive, social, and educational domains. Statements must be descriptive and focus on the member' s abilities.

B. The member' s/family' s resources, priorities, and concerns related to enhancing their member' s well being.

C. The member' s/family' s identification of strengths, resources, needs, concerns, recommendations, and strategies that will assist the member to be successful and become independent.

D. Desired objectives related to the member.

E. Plan to support transitions to/from hospital, rehab, home, school, work, and other appropriate settings in order to receive services.

F. Services recommended that meet the needs of the member and family to achieve the identified objectives, including: provider/person responsible and time frames.

G. Statement of Behavioral Health services needed and the sources of behavioral health services.

H. The signature of the member, parent/guardian, and names, title, agencies, and signatures of other participants/team members, signifying participation. (Families have the right to decline any or all services without jeopardizing other services.)

2.4.1 Initial Individual Service Plan (ISP)

The Family Resource Coordinator shall develop an Initial ISP within forty-five (45) business days of the completion of the member' s intake.

A. Family Resource Coordinator responsibility:

1. Review and synthesize information from assessments, evaluations, pertinent records, family report, and observation.
2. Ensure that culturally appropriate, consistent, family centered practices, and family centered services are provided.
3. Ensure that a translator is available, if necessary, and that forms and meetings are conducted in the family' s primary language.
4. Implement the family centered decision-making process.

5. Obtain a signed Authorization for Release of Information from the member, parent, or guardian.
6. Complete and send the Primary Care Physician (PCP) a Doctor Referral/Authorization.
7. Provide a written copy of the ISP within fourteen (14) business days of development to the family, primary care provider, team members, service providers, and other involved parties identified by the family.
8. Maintain the original Initial ISP in the member's master file.
9. Review the ISP annually, within fourteen (14) business days of the development of the initial ISP.

B. Individual Service Plan (ISP) Completion

The ISP is a working document and may initially address only the most immediate needs of the member/family. The Family Resource Coordinator, in partnership with the family, must update the ISP based on the level of need. Services shall be delivered based upon available funding, family resources, and coverage by a third party payer, or support from other programs (CRS, AHCCCS, ALTCS, etc.).

1. Emergency services may be provided without the full completion of the initial ISP.
2. A full ISP must be completed within forty-five (45) business days of completion of the member's intake. With the completion of a full ISP the Family Resource Coordinator has the responsibility to assure an Authorization for Release of Information form is completed and signed and a Doctor Referral/Authorization Request form is completed and forwarded to the member's primary care physician.

2.4.2 Ongoing Individual Service Plan (Annual ISP)

After development of the Initial ISP, the Family Resource Coordinator has the responsibility for completing an ISP within one year and fourteen (14) business days of the completion of the original ISP. A signed Authorization for Release of Information must be obtained from the parent or guardian annually during the completion of the annual ISP. All team members shall receive a copy of annual ISP.

2.4.3 Review Of The ISP

The Family Resource Coordinator must complete a Review Of The ISP six months after the development of an ISP using the Review Of The ISP form. The Review Of The ISP must be completed within fourteen (14) business days of the pre-established six-month review date which is determined by the completed ISP date. All team members shall receive a copy of the Review Of The ISP within fourteen (14) business days of development.

2.4.4 Changes In The ISP

The family, member, provider, or Family Resource Coordinator may request a change to the current ISP because of a change in the member's need, condition, or service. The Changes in the ISP form is to be used to document changes in objectives, services, or team agreements in the ISP. This form can be completed during a Review of the ISP or it can be completed on other occasions. If completed during a Review Of The ISP the responsible person must sign the form and all team members shall receive a copy immediately. If the responsible person request the change over the phone, or a provider or the Family Resource Coordinator requests the change, the form must be sent to the responsible person to sign and return, via certified mail, return receipt requested, with a self addressed stamped envelope.

2.5 Transfer/Exit

If a family indicates they are relocating to a different geographic region or if the family indicates they do not want to receive services from the TBI/SCI/CYSHCN Family Resource Coordination Program, a Transfer/Exit form is completed. The transfer/exit date and transfer/exit reason is documented on the Transfer/Exit form and on the Family Resource Coordination Detail Sheet of the Billing Invoice Packet.

2.6 Family Resource Coordination

A. The primary role of the Family Resource Coordinator is to support the family in the identification of needs and resources, and to assist them in coordination, collaboration, and communication with multiple service providers. Families are encouraged to direct this process that will lead them to achieve the best possible outcome for the member and family. Development of the initial and ongoing Individual Service Plan(s) and Family Resource Coordination are provided at no cost to the family.

B. A Family Resource Coordinators' role is to establish a collaborative process which assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet TBI/SCI/CYSHCN member's needs, using communication and available resources to promote quality, cost-effective outcomes. Family Resource Coordinators synchronize and connect services and resources for members and families with TBI/SCI/CYSHCN needs to reach an optimum level of wellness, functional capability, and autonomy, and support activities that will empower them to act as their own advocate.

C. A Family Resource Coordinator contacts families as needed/requested by the family to check on the member's/family's condition, services status, the family's availability to complete the ISP (if no ISP has been developed), and documents all contacts with the member/family using Family Contact/Progress Notes.

D. What the Family Resource Coordination Program and a Family Resource Coordinator Can Do

- Listen / be supportive.
- Be respectful of beliefs, ideas and culture
- Provide information and/or educational materials
- Assist the member and/or the family to:
  - Determine priorities
  - Assess resources and needs
  - Identify other/additional resources
  - Navigate the multiple service delivery systems
- Assist completing forms and applications for services
- Identify service providers
- Coordinate services
- Assist with meeting transportation needs
- Identify potential funding sources
- Assist members and families to reach an optimum level of wellness, functional capability, and autonomy, and support activities that will empower them to act as their own advocate

E. What the Family Resource Coordination Program and a Family Resource Coordinator cannot do

- Counsel or advise
- Provide therapeutic services
- Provide mental health services

- Serve as " first responder" or emergency service provider
- Develop an Individual Education Plan (IEP) because:
  - Family Resource Coordinators are not educational or IDEA experts

Families of members with traumatic brain injury, spinal cord injury, and other special health care needs interact with many sectors of the service delivery system:

A. Medical: consisting of primary care and specialty physicians, durable medical equipment providers, outpatient medical treatments such as therapies, visiting nurses, rehabilitation providers, and hospital inpatient care, are all related to and impacted by the specific health coverage of the family, such as private insurance, ALTCS, or AHCCCS/Kids Care;

B. Public Health: programs such as, Developmental Services, Children' s Rehabilitative Services, Head Start, WIC, County Long Term Care Program, and the Behavioral Health system;

C. Education: consisting of numerous special instruction and therapy providers, and the public school system, beginning with preschool, with its own unique requirements and classroom placements;

D. Social Services: programs such as the Division of Developmental Disabilities, Child Protective Services, Healthy Families, Vocational Rehabilitation, and other organizations that provide intervention and family assistance;

E. Community: resources such as transportation, parks and recreation, child care, libraries, parent support and educational organizations such as Raising Special Kids and Pilot Parents of Southern Arizona, parent advocates, vocational opportunities, city and county government offerings, and many other resources;

2.7 Direct Care Services

Funding is available to support member and family service needs through Direct Care Services (DCS). The family and Family Resource Coordinator shall partner in decision-making and shall pursue reimbursement through all other available resources prior to utilizing Direct Care Services funds. Funds provided under this program may not be used to satisfy the financial commitment for services that would have been paid for by another public or private source. When necessary, exceptions may be made to prevent a delay in the receipt of appropriate services. Authorization for Services must be obtained from the Program Manager and Approval or Denial, on an appropriate Explanation of Benefits (EOB) document, prior to the utilization of DCS funds. Authorization of Services and documentation of EOB must be retained in the member' s file when DCS funds are utilized to provide a service.

2.7.1 Allowed Services

With ADHS/OCSHCN Program Manager authorization the following services may be provided to members in the TBI, SCI, or CYSHCN Family Resource Coordination Program. All allowable services must be identified on the ISP and linked to an applicable objective and outcome.

A. Aquatic Therapy
A therapeutic procedure, which attempts to improve function through the application of aquatic therapeutic exercises. These procedures require constant attendance of a therapist educated in performing aquatic therapeutic exercises.

B. Assistive Technology
Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain or improve the functional capabilities of members with disabilities.

C. Audiology
- Identification of members with auditory impairment, using at-risk criteria and appropriate audio logic screening techniques;
- Determination of the range, nature and degree of hearing loss and communication functions, by use of audio logical evaluation procedures;
- Referral for medical and other services necessary for the habilitation or rehabilitation of members with auditory impairment;
- Provision of auditory training, aural rehabilitation, speech reading and listening device orientation and training, evaluation of effectiveness of those systems, including FM systems, training, and other services;
- Provision of services for prevention of hearing loss; and
- Determination of member' s need for individual amplification, including the selecting, fitting and dispensing appropriate listening devices and evaluating effectiveness of those devices.

D. Cognitive Retraining (TBI Family Resource Coordination Program ONLY)
Therapeutic strategy that seeks to improve or restore a person's cognitive skills in the areas of paying attention, remembering, organizing, reasoning and understanding, problem-solving, decision making, and higher level cognitive abilities through the use of verbal, video and computerized teaching techniques.

E. Dental Services
Related to member' s primary diagnosis.

C. Durable Medical Equipment
An appliance, apparatus, or product intended for use in nursing diagnosis or treatment and in the prevention of disease or maintenance or restoration of health that is required to implement the overall plan of care. Durable Medical Equipment generally refers to items that can withstand repeated use and are reusable.

D. Equestrian Therapy
Learning environment/activity that promotes the acquisition of skills in a variety of developmental areas including cognitive, physical and social interaction using horse/motion

H. Family Training, Counseling and Home Visits
Services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the family of an eligible member to understand the special needs of their child and to enhance their child' s development.

I. Health Services
Services necessary to enable a member to benefit from the other intervention services during the time the member is receiving such services. Includes:
- Services such as clean, intermittent urinary catheterization, tracheotomy care, tube feeding, changing of dressings or colostomy collection bags, and other health services; and
- Consultation by physicians with other service providers concerning the special health care needs that will need to be addressed in the course of providing other intervention services.

DOES NOT include:
- Services that are surgical in nature
- Services which are purely medical in nature and
- Medical-health services routinely recommended for all members

J. Household Expenses
Includes utilities and rental expenses

K. Medical Services (Diagnostic Evaluation Only)
Provided by a licensed physician for diagnostic or evaluation purposes only.

L. Medical Supplies
TPN, dressings/splints, etc. when directly related to member's primary diagnosis.

M. Music Therapy
Learning environment/activity that promotes the acquisition of skills in a variety of developmental areas including cognitive, physical, and social interaction, using music.

N. Neuropsychological Evaluation or Rehabilitation (TBI Family Resource Coordination Program ONLY)
Neuropsychological evaluations evaluate multiple areas of functioning. The evaluation is not restricted to measures of intelligence (e.g., IQ) and achievement, but examines other areas of functioning that also have an impact on performance in the classroom, with peers, at home, or on the job. Cognitive functions likely to be assessed include Sensory Perceptual and Motor Functions, Attention, Memory, Auditory and Visual Processing, Language, Concept Formation and Problem Solving, Planning and Organization, Speed of Processing, Intelligence, Academic skills and Behavior, Emotions, and Personality.

O. Nursing Services
- Assessments of health status for the purpose of providing nursing care, including identification of pattern of human response to actual or potential health problems;
- Provision of nursing care to prevent health problems, restore or improve functioning and promote optimal health and development; and
- Administration of medications, treatments, or regimens prescribed by a licensed physician.

P. Nutritional Services
Conducting individual assessments in:
- Nutritional history and dietary intake;
- Feeding skills and feeding problems;
- Food habits and food preferences;
- Developing and monitoring appropriate plans to address nutritional needs of members who are eligible based on above assessments; and
- Making referrals to appropriate community resources to carry out nutritional goals;

Q. Occupational Therapy
Services to address the functional needs of a member related to performance of adaptive development, adaptive behavior and play, and sensory, motor and postural development. Such services are designed to improve the member's functional ability to perform tasks in home, school, and community settings. They include:
- Identification, assessment and intervention;
- Adaptation of the environment and selection, design and fabrication of assistive Orthotics to facilitate development and promote acquisition of functional skills; and
- Prevention or minimization of the impact of initial or future impairment, delay in development or loss of functional ability;

R. Other (Must Provide Explanation)
Includes other services needed to support the member/family in achieving desired outcomes.

S. Personal Assistance
Support activities to assist members in carrying out daily essential living tasks (i.e. bathing, dressing), monitoring individual's condition and functioning level, cueing the member to perform a task.

T. Personal Supplies
Personal supplies needed to address a member's special health care need i.e. Nipples and diapers. Personal supplies need to be directly related to the member's primary diagnosis.

U. Physical Therapy
Includes services to address the promotion of sensory motor function through enhancement of musculoskeletal status, neurobehavioral organization, perceptual and motor development, cardiopulmonary status, and effective environmental adaptation. Such tasks are designed to improve the member's functional ability to perform tasks in home, school, and community settings. These services include:

- Screening, evaluation, and assessment to identify movement dysfunction;
- Obtaining, interpreting and integrating information appropriate to program planning to prevent, alleviate or compensate for movement dysfunction and related functional problems; and
- Providing individual and group services or treatment to prevent, alleviate, or compensate for movement dysfunction and related functional problems.

V. Prescription Medications
Drugs prescribed by a licensed physician to prevent, stabilize, or ameliorate symptoms arising from member's primary diagnosis

W. Provider Co-Pays
For services identified on the Service Plan

X. Psychological Services

- Administering psychological and developmental tests and other assessment procedures;
- Interpreting assessment results;
- Obtaining, integrating, and interpreting information about member's behavior and member and family conditions related to learning, mental health and development;
- Planning and managing a program of psychological services, including psychological counseling for members and parents, family counseling, consultation on development, parent training and education programs.

Y. Respite
An interval of short-term supervision to provide relief to the member's primary caregiver

Z. Social Work Services

- Home visits to evaluate a member's living conditions and patterns of interaction;
- Preparation of a social or emotional developmental assessment of the member with the family context;
- Provision of individual and family-group counseling with parents and other family members, and appropriate social skill-building activities with the member and parents;

- Work with those problems in a member's and family's living situation (home, community and any center where intervention services are provided) that affect the member's maximum utilization of intervention services; and
- Identification, mobilization and coordination of community resources and services to enable the member and family to receive maximum benefit from intervention services;

AA. Speech/Language Therapy
- Identification of members with communicative or oropharyngeal disorders and delays in development of communication skills, including diagnosis and appraisal of specific disorders and delays in those skills;
- Referral for medical or other professional services necessary for the habilitation or rehabilitation of members with the above speech-language disorders; and
- Provision of services for the habilitation, rehabilitation or prevention of the above speech-language disorders;

BB. Translation/Interpreter Services
Oral and/or written services provided to families with limited English proficiency or other communication barriers (sight, sound) during Service Plan development, provider appointments, or other treatment activities. This allows the member/family to obtain maximum benefit from the service.

CC. Transportation & Related Costs
The cost of travel (e.g., mileage or travel by taxi, common carrier or other means) and other costs (e.g., tolls or parking expenses) that is necessary to enable a member and the member's family to receive intervention services.

DD. Vision Services
- Identification of members with visual impairment, using at-risk criteria and appropriate vision screening techniques;
- Referral for medical and other services necessary for habilitation or rehabilitation of members with visual impairment;
- Determination of nature, range and degree of vision loss and mobility functions by use of functional vision assessment;
- Communication skills training, orientation and mobility training for all environments, visual training, independent living skills training, and additional training necessary to activate visual motor abilities;
- Provision for use of vision, orientation and mobility, concept development and other services; and
- Determination of member's needs for individual, low vision optical aids and functional vision assessment.

2.8 Transition

All members and their families move through developmental and non-developmental transitions throughout their lives. Developmental transitions are those changes that occur related to the member's age, developmental skills, and accomplishments. Non-developmental transitions include changes related to life events. Some are anticipated, such as going to school and others are not, such as an acute illness, which requires hospitalization. There are several types of non-developmental transitions in which the Family Resource Coordinator is involved:

The Family Resource Coordinator will:
- Begin transition activities at any time there is a change in setting.
- Work with the family to identify ISP team members to plan the transition.
- Notify the hospital, service provider, school, etc. of the impending transition.
- Coordinate schedules, and notify all participants of the transition meeting well in advance.

Make alternate arrangements for participation for those unable to attend.
- Gather, review, and summarize assessment information and records of progress in order to prepare for transition.
- Collaborate with other team members to identify the need for additional assessment(s).
- Arrange for the family to visit the new service setting or classroom if applicable.
- Provide information to the member/family about potential alternate services.
- Contact the agency, school, etc. and document the start date of services.
- Confirm a successful transition through at least one follow-up contact with the family.

Family Resource Coordination Transition Criteria

Individuals participating in TBI/SCI/CYSHCN Family Resource Coordination shall be transitioned upon the occurrence of one of the following:
- The member and/or their family request an alternative delivery system
- The Contractor recedes out of the family resource coordination service role
- The member ages out
- A family fails to respond to 3 phone calls and 1 written notices of attempt to contact
- Discharge/admission to/from hospital or rehabilitation setting
- School entry, re-entry, drop-out, discharge, or graduation
- Work/Job entry, re-entry, change, or discharge.